IN THE UNITED STATES DISTRICT COURT

FOR THE DISTRICT OF HAWAI'I

HAWAI'I DISABILITY RIGHTS CENTER, in a representative capacity on behalf of its constituents,

Plaintiff,

VS.

CHRISTINA KISHIMOTO, in her official capacity as Superintendent of the State of Hawai'i, Department of Education; and PANKAJ BHANOT, in his official capacity as Director of the State of Hawai'i, Department of Human Services,

Defendants.

Civ. No. 18-00465 LEK-RLP

DECLARATION OF AMANDA KELLY, PhD, BCBA-D, LBA

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- I, AMANDA KELLY, PhD, BCBA-D, LBA, hereby declare:
- 1. I make this Declaration based on my personal knowledge and I am competent to testify as to the matters set forth below.
- 2. I have my PhD in Behavior Analysis and have been a doctorate-level Board Certified Behavior Analyst ("BCBA-D") since April 2013.
- 3. Prior to becoming a BCBA-D, I was a Board Certified Behavior Analyst ("BCBA") since March 2008.

- 4. In addition to behavior analysis, I have worked as a paraprofessional, licensed teacher, and school counselor. I have worked in home settings, public and private schools, residential placements, and community settings for children and adolescents who have social-emotional, cognitive, or behavioral needs.
- 5. I currently serve as the Legislative Chair of the Board of Hawai'i Association for Behavior Analysis ("HABA") and as the Secretary of the Board of Hawai'i Disability Rights Center ("HDRC"). In past years, I served as the President of HABA and the Dissemination of Behavior Analysis Special Interest Group (DBA-SIG) of the Association for Behavior Analysis International.
- 6. I have worked with HABA to advocate and achieve successful licensure of behavior analysis and state-wide Autism insurance reform in Hawai'i, as set forth in detail below.
- 7. BCBAs are required to practice in conformance with global standards in the *Professional and Ethical Compliance Code for Behavior Analysts*, which includes a requirement that BCBAs "rely on professionally derived knowledge based on science and behavior analysis when making scientific or professional judgments in human service provision…" and "uphold the values, ethics, and principals of the profession of behavior analysis." *See*

https://www.bacb.com/wp-content/uploads/170706r_compliance_code_english.pdf (Sections 1.01 and 6.01(a)).

- 8. There is critical, required foundational knowledge that every Behavior Analyst must master prior to entering the practice. This foundational knowledge includes being able to explain and behave in accordance with the philosophical assumptions of behavior analysis, such as: the lawfulness of behavior; selectionism; determinism; empiricism; parsimony; pragmatism; environmental (as opposed to mentalistic) explanations of behavior; distinguishing between radical and methodological behaviorism; and distinguishing between the conceptual analysis of behavior, experimental analysis of behavior, applied behavior analysis, and behavioral service delivery. *See*https://www.bacb.com/wp-content/uploads/2017/09/160101-BCBA-BCaBA-task-list-fourth-edition-english.pdf.
- 9. Behavior Analysis is the core competence for the provision of Applied Behavior Analysis ("ABA") as a treatment for Autism Spectrum Disorder ("Autism").
- 10. ABA has been empirically shown to be effective in a wide variety of areas, including parent training, substance abuse treatment, dementia management, brain injury rehabilitation, occupational safety intervention, among others. ABA was first applied to the treatment of individuals with intellectual

disabilities and autism, so this practice area has the largest evidence base and has received the most recognition.

- ABA services. A RBT is a paraprofessional who practices under the close, ongoing supervision of a BCBA, but the RBT does not design intervention or assessment plans. It is the responsibility of the RBT supervisor to determine which tasks an RBT may perform as a function of his or her training, experience, and competence. The BCBA supervising the RBT is responsible for the work performed by the RBT on the cases they are overseeing.
- 12. In 2015, based on requests from the medical insurance community to formalize the practice of behavior analysis, Hawai'i passed a law for the Licensure of Behavior Analysts (HRS Chapter 465D) (the "Licensure Law").

 A Licensed Behavior Analyst is referred to as "LBA."
- 13. Pursuant to the Licensure Law, Behavior Analysts are required to be licensed beginning on January 1, 2016. HRS §465D-4(a) ("...no person shall engage in the practice of behavior analysis or use the title "licensed behavior analyst" or "behavior analyst" without a valid license issued pursuant to this chapter.").
- 14. I became the first behavior analyst licensed in the state of Hawai'i under the Licensure Law, and I currently remain a Hawai'i LBA.

- 15. The Licensure Law defines ABA as "interventions that are based on scientific research and the direct observation and measurement of behavior and the environment[,]" and the general "practice of behavior analysis" as:
 - ...the design, implementation, and evaluation instructional and environ-mental modifications produce socially significant improvements in human behavior. Practice of behavior analysis includes the empirical identification of functional relations between behavior and environmental factors, known as functional assessment and analysis. Practice of behavior analysis also includes the use of contextual factors, motivating operations, antecedent stimuli, positive reinforcement, and other consequences to help people develop new behaviors, increase or decrease existing behaviors, and emit behaviors under specific environmental conditions. Practice of behavior analysis expressly excludes psychological testing, diagnosis of a mental or physical disorder, neuropsychology, psychotherapy, cognitive therapy, sex therapy, psychoanalysis, hypnotherapy, and long-term counseling as treatment modalities.

HRS §465D-2 (definitions of "Applied behavior analysis" and "Practice of behavior analysis").

16. The Licensure Law authorizes the State licensure board to refuse licensure or discipline a LBA for, among other things, violations of the Behavior Analyst Certification Board's ethical guidelines for responsible conduct. HRS §465D-4(6).

- 17. There are important exemptions to the Licensure Law, specifically for the DOE, as follows:
 - (1) an individual working within the scope of practice or duties of another licensed profession that overlaps with the practice of behavior analysis; provided that the person does not purport to be a behavior analyst; (2) An individual who implements or designs applied behavior analysis services and possesses board certification as an assistant behavior analyst by the Behavior Analyst Certification Board and who practices in accordance with the most recent supervisory and ethical requirements adopted by the Behavior Analyst
 - (3) An individual who directly implements applied behavior analysis services and:

Certification Board under the direction of a behavior

analyst licensed in this State;

- (A) Is credentialed as a registered behavior technician by the Behavior Analyst Certification Board, and is under the direction of a behavior analyst licensed in this State;
- (B) Is a direct support worker who provides autism treatment services pursuant to an individualized education plan on or before January 1, 2019; [or]
- [(C)] Is a direct support worker who provides medicaid home and community-based services pursuant to section 1915(c) of the Social Security Act on or before January 1, 2019;

provided that for purposes of this paragraph, "direct support worker" means a teacher or paraprofessional who directly implements intervention or assessment plans under supervision and does not design intervention or assessment plans;

(4) A family member or legal guardian implementing an applied behavior analysis plan and who acts under the direction of a behavior analyst licensed in this State;

- (5) An individual who engages in the practice of behavior analysis with nonhuman or nonpatient clients or consumers including but not limited to applied animal behaviorists and practitioners of organizational behavior management;
- (6) A matriculated graduate student or postdoctoral fellow whose activities are part of a defined behavior analysis program of study, practicum, or intensive practicum; provided that the student's or fellow's activities or practice is directly supervised by a behavior analyst licensed in this State or an instructor in a Behavior Analyst Certification Board-approved course sequence; or
- (7) An individual pursuing experience in behavior analysis consistent with the Behavior Analyst Certification Board's experience requirements; provided that the experience is supervised by a behavior analyst licensed in this State.

HRS §465D-7 (emphasis added). There is also an exemption for licensed psychologists practicing within their recognized scope of practice, which was strongly advocated for by that group of professionals at the Legislature. All of these exemptions are slated to be repealed on June 30, 2021.

during the 2016 and 2017 Legislative sessions, after the Licensure Law was initially passed in 2015. The DOE pushed that it needed an exemption to the Licensure Law for ABA administered by its teachers and other staff in schools. Along with HABA, I advocated strongly against this exemption, primarily because the DOE does not even provide ABA to its students. The 2016 Legislature did not

grant an exemption to the DOE but did grant them extended time to obtain adequate direct DOE support workers implementing an IEP. There were no exemptions or extension in 2017.

- 19. In January 2017, there were 165 LBAs and 544 RBTs statewide. To my knowledge, none of the LBAs or RBT were employed by the DOE to provide ABA services to students with Autism.
- 20. In 2018, with the January 2019 expiration of their exemption looming, the DOE advocated the 2018 Legislature for a further extension. The Legislature did not grant an extension, but passed Act 205, which directed the DOE to "create an implementation plan to seek reimbursement of any medicaid billable applied behavior analysis the department may provide to students diagnosed with autism spectrum disorder." It further directed the DOE to submit an initial report to the Legislature within 90 days of the July 10, 2018 effective date of the Act (by October 8, 2018) with a detailed plan and then submit subsequent quarterly reports to the Legislature and the Board of Education. I am not aware of any report or detailed plans from DOE.
- 21. For years, the Hawai'i Medicaid program (Quest) and private health plans refused to cover medically necessary ABA services.
- 22. In 2015, the Hawai'i Legislature passed a law requiring private health plans to cover medically necessary ABA.

- 23. The Hawai'i Medicaid program hesitated and it was not until 2016, likely a result of the Federal Court case involving Suzanne Egan (*J.E. v. DHS*), that I began hearing of EPSDT recipients of the Medicaid program receiving coverage for medically ABA services.
- 24. However, I then became aware of a growing number of children who were approved for Medicaid coverage of ABA services, but who were being told that Medicaid would not pay for services during school hours or that ABA during the school day was DOE's responsibility.
- 25. I was not aware of DOE providing any meaningful ABA services to its students in public schools. I had attended numerous individualized Education Plan ("IEP") meetings with DOE on behalf of students with Autism to recommend ABA services for a student which I had performed an individualized assessment and determined needed ABA.
- 26. DOE did not consider my recommendations and I learned that DOE deferred to its "process" by which unqualified, and often unwilling, special education or other resource teachers are told to "assess" students with Autism and make recommendations for the IEP, but specifically not to ever include ABA services in an IEP.
- 27. I also became aware of DOE's practice not to have a qualified BCBA perform functional behavioral assessments ("**FBA**s") for children with

Autism. As a direct result of such failure, there is no way children with Autism are properly being assessed for ABA services and, thus, the ultimate and eventual determination that ABA not be included in a child's IEP has become the norm.

- 28. I have seen DOE refuse parents' reasonable requests for Independent Educational Evaluations ("IEE") by LBAs, going as far to initiate due process against families who request such IEEs. In cases where IEE's have been completed, I have experienced DOE school teams refusing to adopt any of the recommendations made by the LBA, as recently as this month.
- 29. I know of a select few students who have ABA in their IEP and each instance is the result of relentless parent advocacy and due process cases.
- 30. My understanding is that DOE has and continues to have a shortage of employed BCBAs to prepare and supervise ABA service plans. As a result, DOE refuses to include "ABA" in IEPs so that it does not violate the State's Licensure Law for the unlicensed practice of ABA.
- 31. Nonetheless, I have become aware of numerous individuals who have engaged in the unlicensed practice of ABA (mostly in the assessment phase) on behalf of DOE. My ethical duties as a BCBA require me to report these individuals to the licensure board, and I have.
- 32. I have experienced numerous situations where the DOE determines that a child with Autism does not need ABA based only on the DOE's

in-house assessment by a special education teacher, "autism consultant," "autism resource teacher", or some other person who is not an LBA.

- 33. I became aware that in addition to DOE not providing ABA services to its students, it also refuses to allow private BCBAs from accessing DOE students during the school day to provide ABA services, even if such services are entirely funded by private health insurance or Medicaid.
- 34. Based on my experience, about 95% of children with Autism should have some level of ABA services in school to reach their individualized educational goals.
- 35. Between July 12 through 20, 2017, I reached out to Debbie Farmer, the DOE's Special Education Director, regarding ABA services during the school day that had already been approved for coverage by health plans but needed to be provided across settings. Ms. Farmer responded to me on July 18th that:

Parents should be following the process under IDEA and Chapter 60 with the IEP team, for services requested by the parent. If a parent wants the school to consider a service, documentation needs to be provided, so the IEP team can consider the request.

Consistent with your information that these are HIPPA protected services, DHS has sent out a memo dated May 31, 2017 to Quest health providers, including Kaiser and HMSA. The memo states, "If justification is provided indicating the ABA service is medically necessary and approved by the QI (Hawaii's Quest Integration) health plan, the health plan will be responsible to provide and cover ABA services before or after school and when school is not in session.

Attached as **Exhibit 1** is a true and correct copy of my string of email exchanges with Ms. Farmer.

36. I responded to Ms. Farmer that the parents I was aware of had already utilized the IEP process but had been told the "district does not allow this." I clarified that I was the referring provider, that it was my professional recommendation for these clients to receive ABA across settings, and that the health plans had already approved coverage for the services. Ms. Farmer responded to me that:

I realize I have not been clear, please let me clarify. The medical service I referenced was skilled nursing, which is delivered on a school campus. Although this service is medical, parents do not pay for this service through their health insurance, rather this service is funded by DOE during the school day on a school campus. Skilled nursing is a related service under IDEA/Chapter 60, it is documented in the IEP. Skilled nursing on a school campus is considered an educational service protected under FERPA, not HIPPA.

The relevance of the DHS memo, is the unlikely position that both Kaiser and HMSA will treat their members differently based on their income status. I doubt that both health providers would discriminate between Quest and non-Quest members. However, I will verify the position of both health plans, Kaiser and HMSA, to be sure.

The Department's position is that only educational services are delivered within the school day. Those services that are medically necessary, such as skilled nursing, are delivered during the school day on a school campus at DOE expense, documented in the IEP and considered educational services.

Since the services you mentioned are protected by HIPPA and are paid through the parent's health plan, these are not educational services and are not be delivered during the school day on a school campus. The DOE has a specific mission to educate school age children/youth and our schools take this mission seriously.

See <u>Ex.1</u>. Although Ms. Farmer told me that DOE only had to provide educational access, not accommodate medical needs, I knew they were doing neither.

37. On August 3, 2017, I sent an email to Governor David Ige regarding DOE's non-compliance with the Licensure Law and other issues regarding DOE's failures to provide adequate ABA in schools. On October 2, 2017, I received an email from Annie Kalama with the DOE's "Special Needs Section," informing me as follows:

The [DOE] is required to comply with the [IDEA] and Hawaii Administrative Rules Chapter 8-60; and therefore, must ensure that each student's [IEP] is developed by the IEP team and designed to maximize the child's access to and progress in the general education curriculum. Any parent(s)/legal guardian(s) requesting [ABA] services through a healthcare provider during the school day may bring the healthcare plan to the IEP team for consideration. It is the IEP team's responsibility to review the healthcare plan and its educational relevance and benefit to the student regarding accessing and progressing in the general education curriculum. Any recommendations and/or services from the healthcare plan determined to be educationally relevant and included in the child's IEP will be provided by the [DOE].

A true and correct copy of this email, dated 10/2/2017 is attached as **Exhibit 2**.

38. By the beginning of the 2017-2018 academic school year in August 2017, DOE had clearly established that it was their policy not to allow

ABA providers on school campus. Parents testified during 2018 Legislative Session about this issue, but nothing was done to address it.

- 39. Decades of research has demonstrated the efficacy of ABA behavioral health treatment for reducing problem behaviors and deficits and improving functioning of children with Autism, including increasing communication, learning, and appropriate social behavior.
- 40. ABA behavioral health services are necessary for many children with Autism to participate in educational and school related activities in the least restrictive environment.
- 41. ABA is best provided across settings, such as both at home and in school. ABA is less effective if only administered after school when a child is tired.
- 42. There is little to no distinction between, and certainly lots of overlap between, "medical" ABA and "educational" ABA. I do not know of any situations where a child required medical ABA services and not some level of educational ABA.
- 43. ABA consists of critical medical, educational, behavioral, and communication service components, among others, for children with Autism.
- 44. ABA services must be provided in a qualified manner otherwise it would not be truthful to call it ABA. While there are components of ABA that

may seem similar to other therapy, to be truly ABA requires someone trained in ABA to provide the service. Improperly administered behavior analysis can permanently harm a child.

- 45. To be effective, ABA services must planned and overseen by a LBA and administered by a qualified person across settings which means at home, at school, and in other places.
- 46. DOE does not think the Licensure Law should pertain to its teachers, staff, or employees.
- 47. I have been working with parents to advocate for proper ABA assessments and services for children during the school day.
 - 48. I have attended approximately 100 IEP meetings in Hawai'i.
- 49. I have experienced school teams refusing to assess, offering assessments by unqualified persons, failing to include essential team members, denying, delaying, or blocking observations on school campuses, dismissing outside assessments and IEEs completed by reputable experts, failing to accept diagnoses made by medical professionals, failing to qualify children with Autism as eligible for an IEP, forcing families to choose between DOE's offer of FAPE and right to access their medically-necessary care, refusing to reflect related services on the IEP grid, refusing to discuss or include parental concerns, and omitting discussions relating to ABA services from meeting summaries.

- 50. I have encountered and observed persons in Hawai'i engaging in the unlicensed practice of behavior analysis and, in extreme situations, reported persons to the Hawai'i Department of Commerce and Consumer Affairs to prevent irreparable harm to children.
- 51. I have observed that DOE only uses Educational Assistants ("EAs") to provide one-on-one support for its students in school, even for students with Autism who are recommended RBT services by a LBA in an IEE. Part of proper ABA therapy includes the one-on-one individual support by a RBT. DOE cites to the provision in Licensure Law that purportedly exempts it from compliance with certain licensing and training provisions until January 2020. DOE's EAs do not provide adequate ABA services to students with Autism. EAs have no specialized qualifications or training and are not reimbursable by Medicaid, nor are they considered as fungible replacements for RBTs.
- 52. I have experienced numerous situations where DOE has refused to recognize a child's professional Autism diagnosis.
- 53. I have experienced situations where Autistic students are not even considered for IEPs, despite a parent's request and a professional determination that such a child has behavioral issues and needs ABA services during school. Not all students with Autism exhibit problematic behavior under DOE's standards and, thus, those students will not receive an IEP.

- 54. I have experienced numerous situations where parents of a child diagnosed with Autism request that ABA services be included in their child's IEP, but such services are not included.
- 55. I am aware of situations where the IEP "team" members for a DOE-enrolled child with Autism have retaliated against parents for requesting ABA services. Most of the time, a DOE IEP team does not include a behavior analyst professional who is qualified to determine whether a student needs ABA.
- 56. I am aware of, and have spoken with, numerous DOE teachers who are aware of these issues with DOE but too afraid to come forward because they fear retaliation. The HSTA testified on behalf of these teachers during the 2018 Legislative Session, encouraging that DOE should be required to hire LBAs for ABA assessments.
- 57. I have been a vocal critic of DOE's failure to provide qualified ABA services to children with Autism in public schools. I have been retaliated against for advocating for ABA services in DOE by properly licensed professionals.
- 58. During the time from November 2017 through June 2018, I testified numerous times to the Board of Education regarding this issue.
- 59. I have met with numerous lawmakers, testified numerous times before State Legislature, and have written to the Governor regarding this issue.

- 60. To date, DOE has not reached out to HABA regarding the need to contract LBAs for FBAs and ABA assessments for its students with Autism.
- 61. I am not aware that DOE has built up any internal capacity of LBAs or RBTs to provide the level of ABA services that DOE students with Autism currently need, or that DOE has attempted to do so.

I declare under penalty of perjury under the laws of the United States of America that the foregoing is true and correct.

DATED: Honolulu, Hawai'i, November 20, 2018.

AMANDA KELLY